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Designing and evaluating a mobile personal health record application for kidney transplant patients

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ABSTRACT

Background: Due to their close relationships with diabetes mellitus (DM) and hypertension (HTN), kidney transplant patients (KTPs) are constantly facing numerous chronic conditions and self-care challenges. In this respect, a personal health record (PHR) is one of the most important self-care tools, which provides access to self-care services as well as chronic disease management (CDM) through monitoring and learning.
Methods: This applied-developmental research was completed in three phases. The first phase was associated with the minimum data set (MDS), including (A) finding relevant resources from the databases of PubMed, Google Scholar, Web of Science, Scopus, and Science Direct, as well as gray literature, (B) extracting information related to KTP health record (KTPHR), (C) assessing the quality of studies via a rating checklist, and (D) designing an initial KTPHR model and its validation by the Delphi technique based on expert opinions. The second phase also consisted of the development of a KTPHR app for Android. In the third phase, the KTPHR usability was evaluated by think-aloud and heuristics techniques.
Results: The study results comprised of [1] developing the MDS for KTPs with reference to a systematic method and a scoring system (namely, 10 classes and 80 data set elements), and [2] designing and building the KTPHR app with features such as health records, data dashboard, test results, medications, appointments/visits, and training to prolong the life of a transplanted kidney [3], reflecting on usability evaluation outcomes to demonstrate that qualitative evaluation was more reliable for identifying problems than quantitative heuristics. In addition, utilizing the rating checklist revealed that the principles of "flexibility and efficiency of use" had a higher severity than other cases, and the principle of "help users recognize, diagnose, and recover from errors" had a lower severity by itself.
Conclusion: The final KTPHR model was designed through reviewing the related literature, and validation by clinical and basic science specialists to improve self-care behaviors in KTPs, and consequently facilitate and accelerate decision-making by clinicians. Since the final KTPHR model met the main criteria for evaluation purposes, including content validity and usability, it can be used with more confidence and reliability.

1. Introduction

Chronic conditions as the leading cause of disabilities and mortality across the world, accounting for 75% of the burden of health care costs [1], and 71% of the global deaths [2] are drastically rising [1,3,4]. In 2002, the National Kidney Foundation (NKF) also defined disorders in the functions and structure of the kidneys lasting for three months as chronic kidney disease (CKD) [5]. Being characterized as an asymptomatic condition, CKD is known as the silent killer, so with the late emergence of the disease symptoms, most patients go to see doctors at the advanced stages when their kidneys have lost their functions [6,7].

The NKF's Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines accordingly divide patients with CKD based on low stability in the estimated glomerular filtration rate (eGFR) into five stages [5],

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including a person with Stage 5 CKD at the end stage of the renal disease (ESRD) with the eGFR of 15 mL/min or less. At this stage, the kidneys have almost lost their functions and only need hemodialysis (HD) or transplant therapy for their survival [8]. Studies have thus far shown that transplant can lower the risk of heart disease in comparison with HD [4] and even the risk of death in kidney transplant recipients (KTRs) becomes lower in patients undergoing HD; therefore, kidney transplant can be an appropriate elective therapy for ESRD patients [2].

CKD and ESRD are correspondingly known as common health problems [9] and worldwide public health challenges because of their cost burden and limited financial resources [3,6,10–15], which are prevalent not only in developed countries but also in developing nations such as Iran with the low economy [13,14,16]. According to recent studies, the number of patients with ESRD is unexpectedly growing around the world above the annual human population growth at the global scale [17]. CKD is also affecting approximately 10–13% of the adult population in the world [18,19]. In Europe, the ESRD average annual incidence rate is 171 cases per million, and such figures have been reported by 100 and 336 per million in the United Kingdom and the United States, respectively [20]. With reference to official reports, the annual growth in the incidence rate of ESRD in Iran is equal to 11%, and evidence shows that the number of patients will double in the next five years [21]. Moreover, the ESRD incidence and prevalence rates in this country are 53 and 250 cases per million, respectively [22]. About 54% of ESRD patients in Iran are also undergoing hemodialysis, and the rest experiences kidney transplants [23]. These estimates show that kidney disease may be more prevalent than DM by 8.2% [24].

With reference to the reports released by the United States (US) National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), multimorbidity is accompanied by cost burden [25]. Therefore, following the rise in the prevalence rates of obesity, DM, and HTN, the risk of kidney disease also increases [26].

Studies have further shown that patients suffering from kidney disease are facing numerous challenges in terms of self-care, including complex decision-making, frequent hospitalizations [27], the management of blood pressure, weight, total cholesterol, and blood sugar, fluid intake, diet changes, drug compliance, and physical activities. As self-care skills in such patients are at low levels [11], self-care education is a strategy to relieve kidney disease and one of the major goals for public health [11,28], which may soon become part of primary care services [25].

Mobile technology is also extensively used for CDM services [12]. Accordingly, apps developed for self-care via mobiles can boost the efficiency of some important tasks, affect care for CKD in a clinical manner, and support patients' decisions in real time through algorithms created in each behavioral component [29]. CDM, including the services for KTPs, is thus primarily associated with the person, i.e., it is patient-centered. Therefore, the necessity of self-care in KTPs is evident, and some improvements in self-care skills among patients suffering from chronic conditions can definitely put an end to the numerous challenges facing health systems.

Currently, Iran is implementing one of the most successful Kidney transplant programs in the Middle East [30], so that its rate has reached 24 cases per million people [31]. The rates for liver and heart transplants are 0.33 and 0.16 cases per million, respectively. Due to the success of kidney transplantation and the increasing demand of patients for transplantation, the waiting list has expanded rapidly. It is important to note that there has been no waiting list in Iran since 1999 [32].

Most of the patients performed Renal Replacement Therapy RRT are young. A review of existing study conducted the increasing future demands for such therapy in Iran [33].

Providing help during self-care for chronic conditions, particularly CKD is thus possible through a PHR. This tool is extensively available and comprehensible to people [34,35] as a lifelong resource of health information in accordance with the definitions released by the National Alliance for Health Information Technology (NAHIT) and the American Health Information Management Association (AHIMA), which can be exploited for health-related decision-making [36], especially to aid those actively involved in their self-care [37]. Although there is no single path toward a global PHR, the use of common data can be the basic starting point [36].

A PHR lays emphasis on patient empowerment and better patient-doctor interaction to improve health care quality as a reliable procedure to implement an electronic health record (EHR), which can boost clinical decision-making along with comprehensive data collection [38]. PHR also has a large number of potential benefits, including viewing patients' personal health information, reviewing laboratory test results, checking essential drug lists, browsing valid links to authentic health information online [39,40], reducing doctors' workloads and health care cost burden [41], improving health care relationships [39,40,42], relieving anxiety, increasing patient involvement [42], maintaining and improving health care quality [42,43], identifying drug interactions, as well as documenting allergies and controlling drug and food regimens [39,44]. There are also simpler benefits, including appointments and prescriptions [40].

Moreover, a PHR can take account of the features of decision support, which can be effective in the management of patients with chronic conditions [45]. The remarkable thing is that all the benefits of the use of a PHR for health care providers depend on the integrity of PHR and EHR [45].

With regard to upgrading paper-based PHR into electronic ones, there is a consensus that the digitization of health records can help retain information over time, and such information consequently leads to improved availability of health services and their consequences [46]. Therefore, a PHR is currently computer-based. In the future, smartphones, personal digital assistants (PDAs), iPods, and other web-based devices can host PHRs in complete or partial manners [46].

Mobile-based PHR (mPHR) can thus provide patients with the possibility of having access to health information via the Internet or remote devices, including PDAs and mobiles (in particular, smartphones or those with a system with the capability to run common user apps). The growing use of mPHRs among patients also indicates some extensive trends in digitalized health care to raise the popularity of medical mobile-based apps. The mPHRs are quickly on the rise to share information [47].

The minimum data set (MDS), known as one of the emerging tools for data collection purposes, provides accurate access to health data and statistics [48]. As well, designing and implementing the MDS in health care institutions is a preliminary stage of disease information management that can lead to improved quality of care and disease control [48].

The MDS is further defined as an essentially appropriate set of potential data elements to pave the grounds for planning, managing, and evaluating performance. The main goal of all MDSs, as the core elements of health data and statistics, is to ensure that the data can be compared and matched, using standardized data items with the same definitions.

The evaluation of information systems accordingly aims to determine some components, such as user satisfaction, cost-effectiveness, usability, strengths and weaknesses, and even guidance to upgrade the use of these systems [49]. Thus, one of the methods to boost the confidence level and efficiency of such health information systems is their evaluation, as the main element at the first stages of their development [50].

The categories suggested thus far to perform such evaluations are user-centered and heuristic (expert-centered) ones. During the user-centered evaluation process, users normally perform some tasks, and then their interactions with the application are observed and recorded on video. Most of such evaluations are done through video analysis. In addition, user feedback is generally provided with several questionnaires and interviews. On the other hand, heuristics is assumed as an indirect, low-cost, simple, and expert-centered evaluation, in which experts explore the compatibility of the interface elements of a system with reference to a set of principles, called evaluation principles [51].

Therefore, the heuristic type of evaluation is among the methods that help identify usability problems by spending less time and cost, and exploiting even few resources [52]. Therefore, it is more useful and efficient [51].

The researchers in the present study are accordingly to design and evaluate an mPHR for KTPs.

2. Methods

This study was conducted in **three phases** as follows:

The **first phase** was associated with designing the MDS based on the following steps:

A) Searching strategy and screening

Initially, the search strategy was developed based on some keywords (Tables 1 and 2), and the researchers looked for the related resources accordingly. All the retrieved outputs were then transferred to the EndNote, as the main reference management tool. Searching the existing resources through the databases of PubMed, Web of Science, Scopus, Science Direct, and Google Scholar, wherein the researchers adopted a two-stage procedure to identify the studies on for KTPHRs. At the first stage, the above-mentioned databases were searched to identify the articles related to KTPHR, and at the second stage, gray literature, i.e., reports, standards, and guidelines published by related centers and associations were searched using the Google search engine in order to avoid the neglect of dozens of possible relevant studies. It should be noted that no time limits were considered to include all articles on KTPHR. In addition, non-English studies were excluded.

B) Extracting data elements related to KTPHR

Table 1
Keywords.

Patient Health Record	PHR	Renal transplantations
Health Records, Personal	PHR	Kidney Transplantation
Health Record, Personal	Personal EMR	Renal Transplantation
Personal Health Record	Personal EHR	Renal Transplantations
Record, Personal Health	Portable EMR	Transplantations, Renal
Records, Personal Health	Portable EHR	Transplantation, Renal
Personal Health Records	Personal CPR	Grafting, Kidney
Personal Health Information	Portable CPR	Kidney Grafting
Health Information, Personal	Portable health record*	Kidney Transplantations
Information, Personal Health	Portable medical record*	Transplantation, Kidney
Personal Medical Records	Personal health card*	Transplantations, Kidney
Medical Record, Personal	Personal medical card*	
Medical Records, Personal	Portable health card*	
Personal Medical Record	Portable medical card*	
Record, Personal Medical	Personal health record*	
Records, Personal Medical	Personal medical record*	
Self-care	Personal electronic health record*	
Self-care	Personal electronic medical record*	
Self-management	Portable electronic health record*	
Self-administration	Portable electronic medical record*	
Patient participation	Personal computerized patient record*	
Consumer participation	Portable computerized patient record*	
Self-monitoring		

Table 2
Searching strategy.

((((Personal Health Record[Title/Abstract]) OR Personal Health Records[Title/Abstract]) OR Personal Health Information[Title/Abstract]) OR Personal Medical Records[Title/Abstract]) OR Personal Medical Record[Title/Abstract]	1
((Personal Health Record*[Title/Abstract]) OR Personal Health Information [Title/Abstract]) OR Personal Medical Record*[Title/Abstract]]	2
((((Personal Health Record*) OR Personal Health Information) OR Personal Medical Record*) OR PHR)	3
(patient health record*) AND ((Self-care) OR (Self-management)) AND ((Renal transplantation) OR (Kidney Transplantation))	4

The eligible study data were extracted by the researchers, and then the essential information items related to the KTPHRs, including information item and source type were obtained. The information item was thus effective in identifying some items such as BUN, Cr, etc., and the source type could help in assigning the value or score to each data element.

C) Confirming article quality, using a rating checklist with reference to the study entitled "Diabetic personal health record: A systematic review article" [53], the selected studies were evaluated. The details are listed in Table 3. In this sense, the articles, according to the study type, were scored 1 to 4, and then rated. All the studies included in this review were thus checked. Of note, the quality score was given by one of the researchers and the second researcher consequently validated them.

D) Designing the initial KTPHR model and its validation, which was fulfilled using content validity ratio (CVR) and content validity index (CVI), with the help of experts as well as medical informatics and health information-technology specialists. At the end, the data elements obtaining the highest scores in the final KTPHR model were selected.

The **second phase** was associated with designing the mobile-based KTPHR app, which was done by an app professional designer within approximately one to two months. KTPHR app was coded through Java programing language. Its operating system was Android. In order to complete the KTPHR development, about eight online and in-person meetings were further held. The KTPHR interface could also support the patient-centered type.

In the **third phase**, the KTPHR usability was evaluated as follows:

1. KTPHR evaluation by usability heuristics

In this type of evaluation, the app was provided to 20 evaluators, including nephrologists (one person), health informatics and health information management specialists (17 cases), and laboratory specialists (two individuals)

2. KTPHR usability evaluation based on Think Aloud Protocol (TAP)

In this user-centered evaluation process, the app was provided to ten patients who had undergone kidney transplants. They accordingly performed some typical tasks in the form of a scenario described by the research team, in such a way that the app had been installed on their smartphones, and then received some explanations as a scenario. In this

Table 3
Evidence quality scoring system.

Evidence type	Score
Randomized control trial (RCT), meta-analysis, systematic review	4
Case-control, cohort study, quasi-experimental study	3
Non-analytic or observational study (case report and case series)	2
Formal/expert consensus	1

method, the users could say whatever they thought, but were not allowed to consult with other users at all while performing the tasks. All the tasks took place in a completely quiet environment. During the tasks, the users were also filmed, and at the end, all the recorded sounds and videos were analyzed. In order to reflect on why and how users operated, their feedback during the tasks were examined in the form of interviews and focus group meetings, and subsequently utilized to modify and upgrade the app. As a result, these findings were investigated to provide some recommendations for the app redesign. The inclusion criteria for the patients to evaluate the app usability by TAP were both genders, the age range between 20 and 60, convenient ones, residency in the city of Ahvaz, access to smartphones, and holding at least a high school graduate.

3. Results

3.1. The first phase results: Designing the MDS of KTPHR

Among the studies retrieved in the literature review, only 36 resources were selected. In order to determine the PHR structure, the data classes and sub-classes of the existing resources were further extracted and then allocated to proper categories with reference to the scoring system.

Thereafter, the guidelines published by nephrology and kidney transplant associations, articles, and resources were checked to determine the KTPHR structure, complete the main factors required by the patients in the target population based on the PHR classes, and reach the same structure for designing the KTPHR model. In the end, the KTPHR model was designed by the review of the related studies and evidence, and almost eight 2-h meetings, along with confirmation by the supervisor and a nephrologist.

The KTPHR model was then given to clinical and non-clinical experts in the form of a questionnaire to assess its validity.

The frequency of the general characteristics of the clinical and basic science specialists, validating the KTPHR questionnaire, is illustrated in Table (4).

Ultimately, upon a review of the questionnaires, the KTPHR model was designed. With regard to the content of the studies included and based on the CVR obtained, 11 main classes of KTPHR were determined. The details associated with the use of these classes, the number of data items, and the number of the items selected, are provided in Table 5.

The data items related to each class together with their references and scores based on the total values of the evidence are shown in Table 6.

The data elements for the final KTPHR model are illustrated in Table 7.

Table 4
The frequency of clinical and basic science specialists validating the KTPHR questionnaire in terms of their general characteristics.

General characteristics	Value	Frequency
Clinical specialty	Nephrology	1
	Internal medicine	2
	Laboratory sciences	2
	Pathology	1
Basic science specialty	Medical informatics	7
	Health information management	12
Gender	Female	7
	Male	17
Age range (years)	25–35	5
	35–45	11
	>45	8
Work experience (years)	<10	10
	10–20	8
	>20	6

Table 5
Details related to data classes, number of data items, and number of items selected based on CVR.

Data classes	Number of data items	Number of selected data items
Personal data	31	25
Emergency contact	5	5
Provider data	6	6
Clinical data	11	8
Home measurement	13	10
Laboratory test data	27	7
Vaccination data	4	0
Patient lifestyle	4	3
Medication data	16	12
Paraclinical data	6	1
Other	7	4

4. The second phase results: App development

Mobile-based KTPHR App Features.

The KTPHR was a mobile-based app to help KTPs manage their health information and self-care. The data for this app was provided by a review of valid resources such as articles, reports, standards published by international centers and associations. To sum up, the features of the KTPHR app were delineated as follows:

- Emergency contacts: The contact details of patients' close family
- Medical staff information: The contact details of doctors and other medical staff required by patients
- Health records: The list of all present conditions and patients' history of diseases and allergies
- Home monitoring: Recording BS, blood pressure, height, and weight, as well as water intake and urine output
- Medications: The list of drugs taken by patients and their descriptions
- Tests: Patients' laboratory test data registration including their normal and abnormal ranges
- Vaccines: Data registration for patients' required vaccines
- Appointments: Patients' appointments including previous and next ones and doctors' recommendations
- Lifestyle: Data related to exercise, diet, smoking cessation, and lifestyle modifications

Accordingly, the patients could improve their self-awareness and self-care, and even become empowered to cooperate with doctors to manage their disease.

Before designing the app, a needs analysis was conducted based on the questionnaire whose validity was confirmed in the previous step. Then, the first version of the model with the features concerned was verified by the project supervisor in the form of a prototype at several steps based on some considerations and certain validations. Of note, the researchers attempted to have proper validations for each field in view of the type of input data design and prevent any input data entry errors.

5. The third phase results: usability evaluation of KTPHR app

1. App Evaluation by the Usability Heuristics Method

In evaluating the KTPHR app usability by the heuristic method, combined evaluation (qualitative and quantitative) was performed. Of note, qualitative evaluation is used for specialists with sufficient skills in evaluation, and ability to define problems and match them with heuristic principles.

Checklist evaluation is also utilized for those who plan to check some examples listed in the checklist based on Nielsen's 10 main principles with the problems in the app.

For this study, Nielsen's 10 main principles (Table 8) were utilized

Table 6
Scores of KTPHR data elements calculated based on the sum of the values of the resources.

Data classes for KTPHR					
Data class	Data subclass		Data element	Reference	Score
General data	Administrative	Identity	Record number	[53]	4
			Patient's image	[54]	1
			First name	[54–56]	3
			Last name	[54–56]	3
			Date of birth	[53,54,57–63]	13
			Gender	[53,54,57–64]	18
			Blood type (group)	[53–55,65]	7
			Life habits	[54,66]	3
		General information	Birth place	[54]	1
			Occupation	[53,59]	5
			Employment status	[54,55,63,65,67,68]	6
			Marital status	[54]	1
		Address	City	[54]	1
			Address	[54–56]	7
		Call	Home phone no.	[53,54,56]	6
			cell phone no.	[54]	1
		Insurance	Primary insurance	[54,55,63,65,67,68]	6
			Secondary insurance	[54]	1
	Contact	Provider data	Provider	[34,35,45,54,69–71]	12
			Specialized area	[54]	1
			Address	[54]	1
			Phone no.	[54]	1
			cell phone no.	[54]	1
			Email	[54]	1
			Comment	[54]	1
		Emergency contact	Emergency contacts	[34,54–56]	5
			Name	[54,55]	2
			Phone no.	[53,56]	5
			Email	[54,55]	2
			Address	[54,55]	2
			Comment	[34,54–56]	10
Mean					4.22
Clinical data	Medical history	Condition (Past/ Present)	Past medical condition	[54,72]	2
			Present condition	[54]	1
			Family history	[34,35,45,54,56,59,69–71,73]	17
			Surgical history	[54,74]	2
	Allergy		Type	[34,45,54,56,69–73,75–77]	19
			Onset date		
			Reaction severity		
			Verification status		
			Verification date		
			Criticality		
			Symptom		
			Comment		
			Documents		
			Medications/treatments		
Mean					8.2
Home monitoring	Vital signs		Blood pressure	[45,53,55,59,60,62,64–69,72,78–81]	30
			Pulse	[53,55,59,62,65,67,69,72,77,79,80,82]	19
			Temperature	[35,55,69,79,80])	8
	Biometry		Weight	[53–55,57,59,62–67,77,80–83])	23
			Height	[53,57,63–65]	10
			Body mass index (BMI)	[53–55,59,60,62–66,77,79,82]	20
			Waist circumference	[53]	4
	Sugar		Blood sugar (BS)	[45,53,59,60,62–64,66,67,77,81,82,84]	21
			Fasting BS	[63,66,67]	4
			2-h postprandial BS (BS 2HPP)	[63,67]	2
			BS 4pm	[63,67]	2
	Water intake		Water intake	[67]	1
	Urine output		Urine output	[67]	1
Mean					11.15
Laboratory test data	Electrolytes and metabolites		Blood urea nitrogen (BUN)	[68,77,82,84]	4
			Creatinine (Cr) blood test	[53,57,61–64,66–68,77,82,84]	19
			Uric acid (U.A)	[62,66,82]	5
			Sodium (Na)	[84]	1
			Potassium (K)	[77,81,84]	3
	Lipids		Total cholesterol	[53,62,64,66,77,82]	12
			Triglyceride (TG)	[53,62,64,66,77,82]	12
			High-density lipoprotein (HDL)	[53,60,62,64,66,77,82]	14
			Low-density lipoprotein (LDL)	[53,60,62,64,66,77,82]	14
	Glycated hemoglobin (hemoglobin A1c: HbA1c)		HbA1c	[53,59,60,62–64,66,68]	15
	Urine analysis		Micro albuminuria	[53,64,66,77]	9

(continued on next page)

Table 6 (*continued*)

Data classes for KTPHR

Data class	Data subclass	Data element	Reference	Score
		Glycosuria	[53,61]	6
		Proteinuria	[53,57,61,62,66,68,81]	13
		Hematuria	[59,63,68,79]	4
		Pyuria	[63]	1
	Complete blood count (CBC)	White blood count (WBC)	[82,84]	2
		Hematocrit (HCT)	[62,82,84]	4
		Red blood count (RBC)	[60,62,77,81,82,84]	8
		Hb	[66]	5
		Platelets (PLTs)	[84]	1
	Trace metals	Calcium (Ca)	[62,66,77,84]	6
		Phosphorous (Ph)	[62,66,77,81,84]	7
		Magnesium (Mg)	[66,81,84]	4
	Hormones	Thyroid stimulating hormone (TSH)	[53,66]	6
		Parathyroid hormone (PTH)	[66]	2
		Vitamin D3	[54,62,81]	4
Mean				6.96
Vaccination data		Influenza vaccine/flu shot	[53,62,66,82,85]	11
		Cytomegalovirus (CMV)	[62,86]	4
		Hepatitis C virus (HCV)	[62]	2
		Pneumococcal vaccine	[53,62,82,85]	9
		Hepatitis A vaccine	[82,85,86]	9
		Hepatitis B vaccine	[53,62,81,82,85,86]	12
Mean				7.83
Lifestyle		Smoking cessation	[53,59,62,64,66,68,77,82]	14
		Exercise	[56,59,62,64,66,68,70,72,79]	12
		Diet	[45,53,54,56,59,62–64,66,68,69,71,73,74,77,79,82,87]	29
		Education (resources)	[53,82]	5
Mean				15
Medication data	General information	Drug name	[53,54,73,79,82]	8
		Generic name	[54]	1
		Brand name	[73]	1
		Drug form	[54]	1
		Prescription date	[53–55,63,65,67,68,82])	10
		Reason for taking each drug	[82]	1
		Descriptive information for each drug	[35]	2
	Dosing	Frequency	[35,54]	3
		Dose	[35,53,54,76,79,82,88]	12
		Dosage form	[54]	1
	Time	Times of taking drugs	[53,54]	5
	Duration	Start date of a drug	[34,35,54,73]	6
		Ending date of a drug	[34,53,54]	7
	Optional	Other instructions (e.g., taking drugs with food)	[53]	4
		Drug reminder	[34,65,72,73,76,81]	8
		Drug alarm	[70,76,79]	4
		Documents		3
Mean				4.52
Paraclinical data	Imaging	X-Ray	[54,55,59,73,80]	5
		Ultrasound	[54,55,59,62,73,80,84]	8
		Computerized tomography (CT) scan	[54,55,66]	4
		Bone density	[77,82]	2
		Kidney biopsy	[66,84]	3
		Documents	[54,69]	5
Mean				4.5
Others	Follow-up	Appointments	[54,55,65,69]	7
		Visits	[45,54,55,60,65,70,76,79,84,87–89])	15
		Recommendations	[69,70,72,75]	8
		eVisits	[54,72,75,88]	5
		Forums	[68]	1
		Connection with other providers	[68]	1
		Sharing	[54,68]	2

[52].

The evaluators independently reviewed the app, and then recorded the items that did not comply with the given principles. In addition, they weighed the severity of the problems based on the five-point scale in Table 9 [52].

The general characteristics of the basic science specialists validating the KTPHR usability heuristic evaluation are listed in Table 10.

During the quantitative evaluation, the app was examined by nine evaluators, using the exploratory evaluation principles in Table 8. Accordingly, a total number of 177 usability problems, as the sum of the defined ones in Table 11, were identified. In this sense, two problems were common among eight, seven, and six evaluators; six cases had commonalities among five evaluators, eight problems were shared among four evaluators, five cases were common among three evaluators, and sixteen problems had commonalities between two evaluators. Upon merging the common cases, the total number of the problems reduced to 65. The lowest non-compliance with the usability evaluation principles for the KTPHR app was related to the principle of "flexibility and

Table 7
Selected data elements in the final KTPHR model.

Data class	Data element	Data subclass	Data element
General data	(1) Record number (2) First name (3) Last name (4) Date of birth (5) Gender (6) Blood type (7) Personal habits (8) Occupation (9) Employment status	Provider data	(1) Provider name (2) Specialized area (3) Office phone no. (4) Cell phone no. (5) Email (6) Address
	(10) Marital status (11) Address (12) Primary insurance (13) Secondary insurance (14) Home phone no. (15) Cell phone no.	Emergency contact	(1) Contact name (2) Office phone no. (3) Cell phone no.
Clinical data	(1) Medical condition: past/present condition (2) Surgical history (3) Allergy		
Vaccination data	(1) Influenza vaccine/flu shot (2) Pneumococcal vaccine (3) Hepatitis B vaccine		
Patient Lifestyle	(1) Smoking cessation (2) Exercise (3) Diet		
Home monitoring	(1) Blood pressure (2) Pulse (3) Temperature (4) Weight (5) Height (6) BMI (7) Fasting BS (8) Water intake (9) Urine output		
Medication data	(1) Drug name (2) Drug form (3) Frequency (4) Dose (5) Dosage form (6) Descriptive information for each drug/note (7) Times of taking a drug (8) Starting date of a drug (9) Ending date of a drug (10) Other instructions (e.g., taking drugs with food)		
Laboratory test data	(1) BUN (2) Cr blood test (3) U.A (4) Na (5) K (6) Ca (7) Ph (8) Total cholesterol (9) TG (10) HDL (11) LDL (12) Aspartate aminotransferase (AST or SGOT) (13) Alanine aminotransferase (ALT or SGPT) (14) Alkaline phosphatase (ALP) (15) Direct bilirubin (16) Total bilirubin (17) Erythrocyte sedimentation rate (ESR) (18) Serum albumin (19) BK virus (20) CMV (21) Cyclosporine (22) Sirolimus (23) Tacrolimus (24) CBC (25) Urine analysis		
Other	(1) Appointments (2) Visits (3) Recommendations		

Table 8
10 main principles of heuristic evaluation.

No.	Title	No.	Title
1	Visibility of system status	6	Error prevention
2	Match between system and the real world	7	Recognition rather than recall
3	User control and freedom	8	Flexibility and efficiency of use
4	Consistency and standards	9	Aesthetic and minimalist design
5	Help users recognize, diagnose, and recover from errors	10	Help and documentation

Table 9
Rating problems based on their intensity.

Intensity	Title	Description
0	No Problem	No problem
1	Cosmetic	No need to correct unless there is extra time in the project
2	Minor	Correcting this problem is of low priority
3	Major	Correcting is important, so it should have a high priority
4	Catastrophe	Correcting the problem is required before the product release

Table 10
The general characteristics of the basic science specialists validating the KTPHR usability heuristic evaluation.

General characteristics	Value	Frequency
Level of education	Master's student	8
	PhD candidate	4
	Assistant professor	4
Gender	Female	8
	Male	8
Age range (years)	25–35	12
	35–45	2
	>45	2
Academic degree	Assistant professor	4
	Lecturer	12
Work experience (years)	<10	9
	10–20	5
	>20	2
Evaluation method	Checklist	9
	Qualitative	7

efficiency of use" (3 cases, 5%), and the highest amount was associated with the principle of "help users recognize, diagnose, and recover from errors" (11 cases, 17%).

More than 50% of the discrepancies were about the principles of "help users recognize, diagnose, and recover from errors", "consistency and standards", and "user control and freedom".

The mean severity of the problems identified here ranged from 1.5 (small) related to the principle of "match between system and the real world" to 2.7 (large) associated with the principle of "flexibility and efficiency of use". The following is a classification of the usability problems based on the non-compliance principles (Table 11). Finally, the problems identified by the independent evaluators were combined, and the duplicates were removed. They were then summarized in a single list and their mean severity was calculated. In addition, the commonalities of the identified problems among different evaluators were determined.

In the qualitative evaluation, the app was examined by seven evaluators. A total number of 62 usability problems were identified, and as before, the problems identified by the independent evaluators were combined and collected after removing the duplicates. Each instance was then assigned to one of Nielsen's 10 main principles.

During the qualitative evaluation, as illustrated in Table 12, one of

Table 11
KTPHR usability problems by their commonality among evaluators, and their mean severity according to the quantitative heuristic evaluation method (checklist).

No.	title Heuristic	Sum of problems	Nine evaluators	Eight evaluators	Seven evaluators	Six evaluators	Five evaluators	Four evaluators	Three evaluators	Two evaluators	One evaluator	Total	Mean severity	Problem severity
1	Visibility of system status	12	–	1	–	–	–	–	–	–	4	5	1.9	Small
2	Match between system and the real world	8	–	–	–	–	–	–	–	2	4	6	1.5	Small
3	User control and freedom	25	–	–	–	–	1	2	2	1	2	8	1.8	Small
4	Consistency and standards	18	–	–	–	1	–	1	–	1	6	9	2.0	Small
5	Help users recognize, diagnose, and recover from errors	36	–	1	1	–	–	2	1	5	1	11	2.1	Small
6	Error prevention	23	–	–	–	1	1	1	1	2	1	7	2.6	Large
7	Recognition rather than recall	8	–	–	–	–	–	–	1	2	1	4	1.8	Small
8	Flexibility and efficiency of use	11	–	–	–	–	1	1	–	1	–	3	2.7	Large
9	Aesthetic and minimalist design	10	–	–	–	–	1	–	–	–	5	6	2.4	Small
10	Help and documentation	26	–	–	1	–	2	1	–	2	–	6	1.8	Small
	Total	177	0	2	2	2	6	8	5	16	24	65	2.0	Small

them was shared between five evaluators and three cases between two evaluators. Therefore, after merging the common cases, their total number reduced to 54. In this evaluation, the lowest non-compliance with the principles of usability evaluation in the KTPHR app was related to the principle of "help users recognize, diagnose, and recover from errors" and "aesthetic and minimalist design" (1 case, 2%), and the most was associated with the principle of "visibility of system status" (24 cases, 44%). More than 50% of the discrepancies were related to the principles of "visibility of system status" and "consistency and standards."

As depicted in Table 13, six problems were identified in the usability evaluation of the TPHR app by a laboratory specialists.

6. App Evaluation of by TAP

To evaluate the KTPHR app usability, 10 people participated, two of whom were female, and three people were male. Considering the level of education, two cases were holding a bachelor's degree, two had a high school graduate, and one was holding a master's degree. The mean age of the patients was 37 and the mean evaluation sessions were 16 min. The general characteristics of the KTPs participating in the evaluation of the KTPHR app usability are shown in Table 14.

7. Discussion

Initial research also showed that KTPs' data collection has not been so far done in an organized and standardized manner. Accordingly, this study was the first attempt, to the best of the authors' knowledge, to develop a KTPHR model in Iran. Since there was no standard case in Iran, a review of evidence including articles, international reports, standards, and guidelines was completed to prepare the initial KTPHR model. Over recent decades, the use of PHR is rapidly expanding.

From AHIMA's perspective, developing a common dataset can be a starting point although there is no single path to global PHR [90]. In this study, evidence related to the data elements of KTPHR was thus checked and the results were validated by clinical experts. The present study was the first attempt with a more comprehensive MDS in Iran, to the best of the authors' knowledge.

Iran is one of the countries with the highest number of kidney transplants in the Middle East [91]. To have the optimal management of a kidney transplant, the data were further organized using a standard procedure. The validation of the findings obtained from a review of the evidence in accordance with the scoring system by Azizi et al. was accordingly suggested [53].

The evidence of the review results showed a wide variety of data classes in the final model, including general data, medical staff data, emergency contact data, home measurement data, laboratory test data, medication data, clinical data, vaccination data, lifestyle data, and others. Among the mentioned data classes, lifestyle and general data had received the most and the least citations, respectively. In addition to the gender data items, date of birth and address (general data), medical staff data, emergency contact data, blood pressure, fasting BS, and BMI (home monitoring), Cr, HbA1c, HDL (laboratory test data), drug dosage and description (medication data), allergy and treatment outcomes (clinical data), influenza and hepatitis B vaccine (vaccination data), and diet (lifestyle data) had been mostly cited. While patient's image and place of birth (general data), medical staff data, emergency contact data, water intake and urination (home monitoring), Na, K, and pyuria (laboratory test data), brand name and drug form (medication data), comorbidities (clinical data), HCV and CMV vaccine (vaccination data), and exercise (lifestyle data) were the least cited. According to the researchers, no similar study was found for comparison purposes.

A review and comparison of the MDS in the initial KTPHR model and the one derived from clinical and non-clinical experts' opinions also resulted in striking findings. This review demonstrated that the data elements derived from the evidence were closely associated with non-clinical experts' opinions and overlapped with the MDS, but the MDS

Table 12
Results of qualitative heuristic usability evaluation.

No.	title Heuristic	Sum of problems	Seven evaluators	Sic evaluators	Five evaluators	Four evaluators	Three evaluators	Two evaluators	One evaluators	Total
1	Visibility of system status	25	–	–	–	–	–	1	23	24
2	Match between system and the real world	2	–	–	–	–	–	–	2	2
3	User control and freedom	2	–	–	–	–	–	–	–	2
4	Consistency and standards	14	–	–	1	–	–	–	9	10
5	Help users recognize, diagnose, and recover from errors	1	–	–	–	–	–	–	1	1
6	Error prevention	6	–	–	–	–	–	1	3	4
7	Recognition rather than recall	2	–	–	–	–	–	–	2	2
8	Flexibility and efficiency of use	5	–	–	–	–	–	–	5	5
9	Aesthetic and minimalist design	1	–	–	–	–	–	–	1	1
10	Help and documentation	4	–	–	–	–	–	1	2	3
	Total	62	0	1	1	0	0	3	50	54

Table 13
Evaluation of the heuristic usability of the KTPHR app by a laboratory specialists.

No.	Problem
1	It is better to prevent the entry of the impossible values. Except for the Ca, most tests are fine.
2	Some laboratories report urea and some Bun. It is better to explain the difference between both.
3	Determine the CMV test type if it is IgM or IgG.
4	The single cyclosporine has not been written.
5	It is better to consider the borderline or suspicious values for tests with positive and negative results, such as BKV.

Table 14
The general characteristics of KTPs (n = 5) participating in the KTPHR app usability evaluation by TAP method.

General characteristics	Value	Frequency
Level of education	High school graduate	6
	Associate's degree	1
	Bachelor's degree	3
Gender	Female	4
	Male	6
Age range (years)	20–30	1
	30–40	7
	40–50	2
Time (minutes)	14–16	5
	17–18	4
	>=19	1

elements obtained from studies and evidence were in conflict with clinical experts' opinions. Of note, the data elements of water intake and urine output (home monitoring) had the least citations, but they were placed in the MDS in the final model as advocated by clinical experts. Moreover, the researchers considered this paradox coming from expert opinions, native to Khuzestan Province, Iran, due to its weather conditions and climate.

The validation results also indicated that the majority of the data items related to nine data classes were important and very important as stated by clinical experts. Moreover, there were items, which had been less cited but had been assumed important in expert opinions; therefore, their comments were of a top priority compared with other validations.

Comparing both evaluation methods, the researchers concluded that qualitative evaluation was more reliable in identifying problems. As well, women could identify more problems than men. Using the checklist evaluation, only three problems (minimum number) in the principle of "flexibility and efficiency of use" were identified by nine evaluators, but due to the high weight of severity, the problems were assumed greater than others. Moreover, in the principle of "help users recognize, diagnose, and recover from errors", eleven problems were identified (maximum number), but it had a smaller severity by itself due to the low weight of severity.

The study results suggested a model for KTPHR tools to involve patients in their self-care process. First, the most important information elements required by the KTPHR tool to improve self-care activities related to KTPs were identified, and then evaluated from the perspective of patients and specialists as well as medical staff, which is a challenge to them.

Self-care behaviors refer to decisions and activities by a person to deal with a health issue or promote health status. There are numerous self-care models, whose common feature is that patients are placed at the heart of health management. As a whole, the large number of KTPs, particularly young ones, highlights the importance of self-care for this age group.

The results of this study implied the positive influence of this app on the literacy of KTPs as well as their self-care. Overall, self-care was examined from several perspectives, including distinguishing normal data from abnormal ones based on all colors and warnings, changing information based on time intervals, providing information about previous measurement values, and giving information regarding the history of measurement date and time.

Few studies have been thus far conducted in relation to PHR and self-care. The important thing originates from different aspects of self-care in various investigations. Most studies have so far reflected on the positive effects of PHR, although some have not noted such effects [92]. Therefore, researchers have shown that such controversies might have several reasons, more importantly, app design methods, research designs, and study times. Consequently, the results of these studies have been affected by some limitations and biases. Since there were few studies on PHR and KTPs, a systemic review of the effectiveness of PHR in KTPs can be useful.

Research strengths

1. Developing a KTPHR tool based on evidence (scoring system)
2. Validating a KTPHR tool in partnership with clinical and non-clinical experts
3. Incorporating expert opinions and evaluating user interface through usability techniques for frequent modifications and refinement of a KTPHR app

Limitations

1. Since the final KTPHR model was validated by local experts, much care should be taken to extend it to other countries.
2. One of the limitations of the study was the criterion of patients' inclusion in TAP under the title of patients' computer literacy. Topics such as digital divide, computer literacy, age, and interest in

technology in mobile-based interventions can be usually very effective in recruiting patients. Younger people with digital literacy and those with Internet access also tend to participate in such studies. This study was no exception. Such a tendency could lead to biases in the findings; therefore, this study did not report the actual distribution of the statistical population.

3. Given the nature of the study, the researchers repeatedly requested the patients to participate in the study to review the app, which reduced their desire to contribute to this research. To address such issues, some financial incentives, such as free laboratory tests and appointment fees, were used.

Conclusion and suggestions

Considering the review of evidence and validations by clinical and non-clinical experts, the final KTPHR model was developed to improve self-care skills in KTPs. However, to help KTPs benefit from KTPHR, this tool was implemented and evaluated on these patients after frequent modifications of the user interface via usability techniques.

Future studies are thus suggested to evaluate this tool in a large-scale manner in health care centers. In addition, this app can be utilized for other patients under the CKD category. Moreover, the present study methods and the results can provide the grounds for similar research with different topics, aimed at promoting self-care in patients using web- or mobile-based tools.

Authors' contributions

Amirabbas Azizi is the principal investigator and conceived the trial. He was responsible for overall administration of the grant. Amirabbas Azizi and Leila KaboutariZadeh were primarily responsible for development of the DPHR app. Ahmad Azizi and Ali Ghorbani assisted in Evaluation. All authors participated in the critical revision and protocol design.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Abbreviations

DM	Diabetes Mellitus
HTN	Hypertension
Ktps	Kidney Transplant Patients
PHR	Personal Health Record
CDM	Chronic Disease Management
MDS	Minimum Data Set
KTPHR	KT Personal Health Record
NKF	National Kidney Foundation
CKD	Chronic Kidney Disease
KDOQI	Kidney Disease Outcomes Quality Initiative
eGFR	Estimated Glomerular Filtration Rate
ESRD	End Stage of The Renal Disease
HD	Hemodialysis
KTRs	Kidney Transplant Recipients
US	United States
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion
BS	Blood Sugar
NAHIT	National Alliance for Health Information Technology
AHIMA	American Health Information Management Association
EHR	Electronic Health Record
PDAs	Personal Digital Assistants
mPHR	Mobile-Based PHR
CVR	Content Validity Ratio
CVI	Content Validity Index

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